

# An assessment of quality of life and economic benefit



Devon Partnership  
NHS Trust

This report was written jointly by Brain in Hand and the Devon Partnership Trust using data captured during the trial in November 2013 and interviews with the research and clinical team. It includes input from a series of sessions with users to gain feedback on their experience and provided input for the next generation of Brain in Hand, all of our evaluations and studies contribute to the ongoing development of our system.

**Brain in Hand** has been designed to improve outcomes and save money. Since its launch, we have engaged with researchers, commissioners, end users, and the academic community to understand the impact it makes and its acceptability to users.

Research on digital support systems in the area of autism and mental health is nascent. The evidence base is growing, but there is much that is not known and, in many regards, traditional research methods are not suitable.

Mindful of these challenges, there are three principles that inform research and development at Brain in Hand:

- (1) Make the most of existing published research to inform product development
- (2) Be nimble: make the most of every opportunity to gather data and get insight on how Brain in Hand is working
- (3) Be open to collaboration with partner organisations and academic institutions.

Our research programme is informed by the NICE Evidence standard framework for digital health. We have strong evidence for Tier 2 of the standard and are working towards Tier 3a.

**Contact: 01392 247909**  
[info@braininhand.co.uk](mailto:info@braininhand.co.uk)  
[www.braininhand.co.uk](http://www.braininhand.co.uk)

**Authored by**  
**Devon Partnership NHS Trust**  
**Brain in Hand Ltd**

# Economic and legislation background

Autism or Autistic Spectrum Condition (ASC) is a lifelong developmental disability with a range of impacts on health, economic wellbeing, social integration, and quality of life for the individual. Some 500,000 people in the UK are known to have autism, of which 350,000 are adults (1), with 75% being male (2). The economic costs of autism in the UK were reported in 2007 to be £28.2 billion annually, with the costs of individual support and care ranging from £33,000 to £98,000 per annum dependent on the level of functioning (high or low) within the autism spectrum(3). Lifetime costs for an individual range between £3.1 million to £4.6 million per person. This data has been published by the Centre for the Economics of Mental Health, King's College London in partnership with the London School of Economics and University of Kent (3).

These costs are significant and any intervention aimed at reducing these costs is to be welcomed. Such intervention however, must impact positively on individual wellbeing, health, social integration and quality of life of people with autism, as well as have demonstrable cost benefit advantages.

The Department of Health (DoH) issued a strategy paper on 'Adult Autism' (4). This aligns with the National Audit Office report on Autism in 2009 (1). The conclusions and recommendations of the DoH paper focus on statutory local responses, which NHS services, Local Authorities and businesses are mandated to address in order to show active support for people who are autistic through adulthood.

## *The mandated requirements include:*

- Effective use of information to plan and provide services for adults with autism and their carers
- Transitions of young people who are autistic to adult services
- Diagnosis and support for people who are autistic
- Employment and related support for Autistic individuals
- Social support (e.g. mentoring as opposed to course related to support) for autistic students in further and higher education

Devon Partnership Trust, one of the leading NHS mental health trusts in England, was selected to assist in undertaking a usage study in 2012 in order to evaluate Brain in Hand in terms of operational use in the community setting.

In total 39 subjects were enrolled in the study for a 20 week period. Brain in Hand was evaluated for acceptability and use in the community setting (qualitative descriptive data). In addition this study conducted a preliminary evaluation of Brain in Hand and its impact on quality of life and economic benefits at a case based level (5,6).

The study covered subjects from both independent and supported living environments: 24% of the study group living on their own and 76% with family or other residential/carer support. Ten of the group attended college education, two were in full-time employment, three in part-time or voluntary work and the remainder not working, but involved with daily social activities.

As such this group of users were representative of the key groups of adults with autism targeted by the Government Strategy papers of 2009/10. The contrasting groups of those with autism living in independent as opposed to supported accommodation gave additional insights into how Brain in Hand might be used in different social settings.

## Results: Qualitative Impacts

### *Quality of Life and Anxiety*

As well as providing information on how Brain in Hand is used in practice, the data collected provided key evidence on the positive benefit of Brain in Hand with respect to clinical impacts, in particular on quality of life and anxiety levels.

Of the 22 people still using the system (either still on service evaluation or continuing use after the trial) some 77% of participants (n=17) said that their use of the system had a very positive impact on their lives (5).

- Enabling people to get on with their day
- Reducing anxiety by knowing there is someone to talk to
- Reducing loneliness
- Improved support and enabling a better understanding of anxiety and how to manage problems.

*The four main positive impacts reported*

Brain in Hand help service user manage anxiety for the majority of the users in two ways:

- By prompting them to assess how they were feeling through the mood monitor (traffic light) system, helping them think and reflect
- By making people feel supported because they knew someone was available to talk to if needed (mentor service).

It is evident that Brain in Hand enabled people to live more positive lives. Indeed in the usage study people who were autistic were helped through some significant transitions such as moving house, starting a job, getting into university, all with lower levels of anxiety than expected.

This study also aligned with the National Audit Office analysis and focus on service solutions that improve outcomes for people who are autistic and their carers by:

- Increasing the likelihood for independent living
- Increasing the likelihood of being in employment
- Reducing the incidence of mental health problems (e.g. anxiety).

Quality of Life Inventory (QOLI) was used on a subset of 8 users to evaluate quantified improvements in well-being and self-esteem.

2 of the 8 had decreased scores showing a negative impact or change over the usage study duration on their quality of life. One of these individuals lost their job, and the other was suffering side effects of new medication. As such it is not surprising that despite the Brain in Hand intervention a decrease in quality of life scores was recorded in these individuals.

In the remaining 6 users positive increases in QOLI scores were noted and ranged from +1 to +48% improvement over the 20 weeks, with an average improvement of +20%.

QOLI is used as a baseline measure of well-being on a regular basis by the Devon Autism and ADHD service involved in this study. The service experience is that QOLI scores are not expected to change over time in people with autism. However in this study positive trends were noted providing preliminary indications that Brain in Hand was having a positive and tangible benefit on self-esteem and well-being as evidenced through quantified and established measures. It would be useful to conduct further work in this area.

## Quality of Life Summary

This study has demonstrated that there are positive trends in QOLI measures that quantify life satisfaction and wellbeing when people with autism use Brain in Hand. This is further supported by qualitative evidence from users which demonstrates that Brain in Hand improves their quality of life and independence. For carers and healthcare professionals feedback also indicates improvements in efficiency and effectiveness of existing support (5).

Further work in this area would help build evidence in this complex but important area of measuring self-esteem in people with autism and how new technologies such as Brain in Hand can positively influence outcomes.

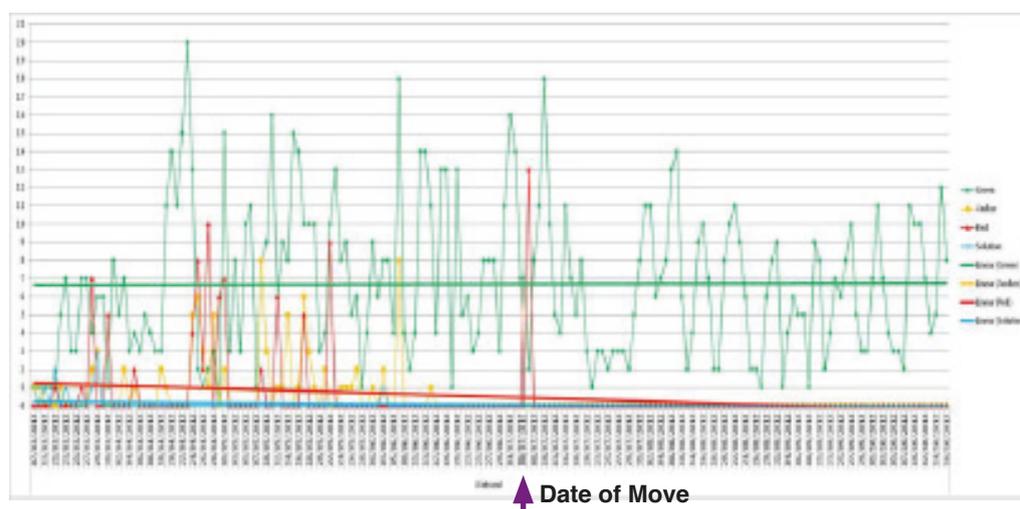
# Economic Assessment

Two case studies have been collated in order to demonstrate the real economic impact of Brain in Hand (6).

## Case 1 (AW)

This relates to an individual who used Brain in Hand as part of an integrated support service. It demonstrates the relevance of Brain in Hand to an individual transitioning from support services into independent living. The Brain in Hand schedule and the 'traffic light anxiety monitor' helped establish control and to manage anxiety for this individual. The graph below shows 'traffic light' usage reflecting a reduction in the need for a mentor as indicated by the decrease in both amber and red line spikes. This was despite the fact that the trial of brain in hand was being used during a period running up to moving home from supported to independent living.

Table showing AW's use of traffic light monitor and date of house move.



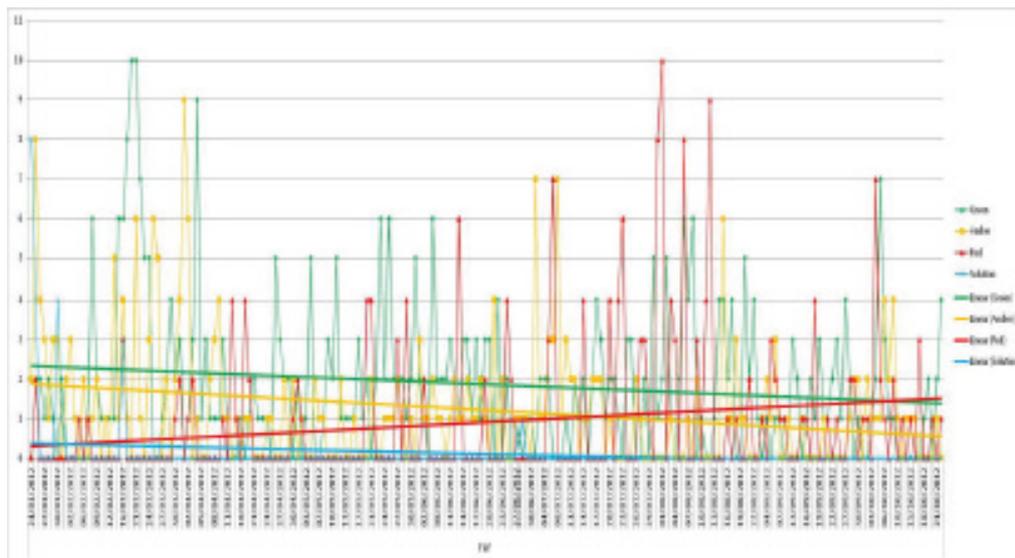
Interviews with AW provided feedback that Brain in Hand had made him feel 'safe' before, during and after the move. Ahead of moving, staff confirmed a noticeable reduction in dependency on their service which was maintained after the move.

The change from residential to independent living saves between £300-500 per week in social care costs. This saving of £15,600- £26,000 per annum is significant and more than offsets the cost of brain in hand at £20 per week or £1000 per annum: a Brain in Hand mentoring service (an optional extra) adds a further £20 per week. In this case study a complete Brain in Hand service (including mentoring) provides a minimum net saving of £13,600 per annum or 7.8 x saving and return on investment.

## Case 2 (FF)

This case study described a highly complex and intensive user of health and social care services. The use of Brain in Hand led to a marked reduction in the level of contact required by health care professionals and in particular crisis services (for people threatening self-harm). Weekly savings of between £500-800 per week have been established for this person where Brain in Hand replaced some 3-4 contacts per week which would involve several hours of clinical support intervention and liaison and write up. For FF an annual saving range from £26,000-£41,600 is calculated. A minimum saving taking into account Brain in Hand costs provides a minimum net saving of £24,000 per annum, or a x12 saving and return on investment. Brain in Hand for this user is replacing the use of mental health service interventions contact (supporting the user differently and more cost effectively). The usage graph therefore is more erratic and shows an increasing number of red spikes as the subject relies on Brain in Hand as a form of support.

Table for FF.



# Professional Perspective

Through interviews with healthcare professionals involved with the usage study the following perspectives were obtained.

There has been no viable and cost effective offering to support people with ASC/Asperger's until now. Brain in Hand offers a credible and acceptable intervention, is well used and highly appreciated by users, carers and clinicians (5). Whilst further work will be beneficial for research including applications across other mental health areas, this Devon Partnership Trust study provides good evidence that Brain in Hand can improve quality of life and has real economic benefit in a range of situations.

Brain in Hand also provides an opportunity to care for the right people at the right time, and respond to user needs intelligently, improving both effectiveness and efficiency of support services. Additionally Brain in Hand provides real-time information for support care plans in a personalised and tailored manner to better inform clinical and support teams (5).

## Summary

For users Brain in Hand becomes a critical friend to allow them to deal with life situations with confidence, independence and control, giving individuals greater self-esteem and sense of being effective in the world.

Brain in Hand addresses the National Audit Office challenge for service solutions to improve outcomes for people who are autistic. It has been demonstrated that Brain in Hand enables people to get on with their day by better managing anxiety, improving self-esteem, self-awareness and supporting independence. Both qualitative and quantitative measures of quality of life demonstrate the positive impact of Brain in Hand and preliminary economic assessments show that Brain in Hand has a significant economic benefit with reduction in health and social resources and associated costs.

Brain in Hand reduces the need for clinical support and associated cost, allowing limited resources to be deployed elsewhere. The application to education and employability is a key area for Brain in Hand use as only 15% of people with autism have a job, yet 79% of people with autism want to work, but have not had the right support to make their ambition a reality (8). Brain in Hand provides technological solutions so more people can be more independent and contribute more in their community.

## Feedback from professionals in the study

*“Brain in Hand allows us to have more focus, and target the right people at the right time”* **Lead Psychologist, Devon Autism and ADHD Service**

*“We have important stories and qualitative indicators which show Brain in Hand has improved quality of life for people who are Autistic.”* **Director of Research and Development, Devon Partnership Trust**

*“Brain in Hand reduced clinical contacts to 1-2 a week compared to 3-5. Assuming clinical contact costs between £100-200 each contact, Brain in Hand provides a significant saving.”* **Devon Partnership Trust lead investigators for Brain in Hand trial**

*“Often you’ve done a certain amount of work with someone – through health or social services – and that contact comes to an end after a certain period. Brain in Hand is something that people can have with them and use on-going. It can take forward that work, providing support and contact, so they’re not just cut-off.”* **Clinical Psychologist for Adults with Learning Disabilities**

Please visit [www.braininhand.co.uk](http://www.braininhand.co.uk) for more information.

### References

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- 8 The National Autistic Society. Facts and figures, NAS website The undiscovered workforce 2013.

Contact: 01392 247909

info@braininhand.co.uk or visit [www.braininhand.co.uk](http://www.braininhand.co.uk)

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